



## **CRIAH Tools for Collaboration**

An initiative of The Coalition for Research to Improve Aboriginal Health (CRIAH) to collect and make available resources and guides to assist researchers to respectfully and appropriately approach and engage Aboriginal communities throughout the research process.

Version 2

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## Tools for Collaborative Research

Research has the potential to lead to improvements in Aboriginal health by informing and changing policy and practice. Historically, however, much of the research which has been conducted in this area has been conducted *on*, as opposed to *with* Aboriginal communities. Too often, research has not been conducted in a respectful manner, has not addressed Aboriginal priorities, and has been of no benefit, or even harmful, to participating communities.

This resource has been commissioned by the Coalition for Research to Improve Aboriginal Health (CRIA) in order to assemble a set of tools to facilitate appropriate collaboration between researchers and Aboriginal communities. Background information is also provided for the benefit of new researchers in the field. This document is aimed primarily at providing researchers with some of the information they need to work in partnership with Aboriginal communities.

The National Health and Medical Research Council have assembled a document designed to provide communities with the information they need to understand the research process and ensure the research they are involved in is beneficial to them:

National Health and Medical Research Council. 2005. ***Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics***. Canberra: Commonwealth of Australia.

<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e65.pdf?q=publications/synopses/file/s/e65.pdf> (accessed online August 2012)

# 1. Background

## a) History and reviews of Aboriginal health research

- Humphery K. 2000. ***Indigenous health and 'Western research'***. VicHealth Koori Health Research & Community Development Unit Discussion Paper No. 2. Victoria: University of Melbourne.
- Dunbar T, Scrimgeour M. 2005. ***Ethical assessment of Indigenous health research: a review of the literature***. Onemda VicHealth Koori Health Unit Discussion Paper No. 14. Victoria: University of Melbourne.
- Henry J, Dunbar T, Arnott A, Scrimgeour M, Murakami-Gold L. 2004. ***Indigenous research reform agenda: a review of the literature***. Cooperative Research Centre for Aboriginal and Tropical Health Links Monograph Series 5. Darwin: CRC Australia.
- Thomas D. 2001. ***The beginnings of Aboriginal health research in Australia***. VicHealth Koori Health Research & Community Development Unit Discussion Paper No. 3. Victoria: University of Melbourne.
- Stewart P, Shibasaki S, Anderson I, Pyett P, Dunbar T, Devitt J (2006). **Aboriginal and Torres Strait Islander participation in ethical review of health research**. *Australian and New Zealand Journal of Public Health* 30 (3): 291-292.
- Sanson-Fisher R, Capbell E, Perkins J, Blunden S, Davis B (2006). **Indigenous health research: a critical review of outputs over time**. *MJA* 2006; 184 (10): 502-505.

## b) Terminology issues

- New South Wales Department of Health. 2004. ***Communicating positively: a guide to appropriate Aboriginal terminology***. Sydney: NSW Department of Health.
- Kelly J (2006). **Is it Aboriginal friendly? Searching for ways of working in research and practice that support Aboriginal women**. *Contemporary Nurse Journal* 22: 317-326.

- Humphery K (2001). **Dirty questions: Indigenous health and 'Western research'**. *Australian and New Zealand Journal of Public Health* 25(3): 197-202.

### c) Ethical issues

- Kaufert JM, Glass KC, Freeman WL, LaBine L. 2004. **Background paper on issues of group, community or first nation consent in health research**. Ottawa: The Canadian Institutes of Health Research.
- National Aboriginal and Islander Health Organisation. 1987. **Report of the national workshop on ethics of research in Aboriginal health**.
- National Health and Medical Research Council. 2003. **Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research**. Canberra: Commonwealth of Australia.

### d) Frameworks for working with Aboriginal communities

- Waples-Crowe P, Pyett P. 2005. **The making of a great relationship: a review of a healthy partnership between mainstream and Indigenous organisations**. Melbourne: Victorian Aboriginal Community Controlled Health Organisation.
- Hurley A. 2003. **Respect, acknowledge, listen: practical protocols for working with the Indigenous community of Western Sydney**. Sydney: MLC Powerhouse Design Studio.
- Dunbar T, Scrimgeour M. **Ethics in Indigenous research – connecting with community**. *Journal of Bioethical Enquiry* 2006; 3(3):179-185.

- Canadian Institutes of Health Research and the National Council on Ethics in Human Research. ***Respecting Aboriginal communities in health research. New standards for the conduct of health research involving Aboriginal people. A researcher and ethics board education module.*** [http://www.wlu.ca/documents/21499/Ethics\\_Protocols\\_-\\_Aboriginal\\_Peoples\\_Doris\\_Cook.pdf](http://www.wlu.ca/documents/21499/Ethics_Protocols_-_Aboriginal_Peoples_Doris_Cook.pdf) (accessed online August 2012).
- Tuhiwai-Smith L (1999). **Decolonizing Methodologies: Research and Indigenous Peoples.** Dunedin: Zed Books/University of Otago Press.
- Kowal E, Anderson I, Baile R (2005). **Moving beyond good intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research.** *Australian and New Zealand Journal of Public Health* 29 (5): 468-470.
- Dunne E. ***Consultation, rapport, and collaboration: essential preliminary stages in research with urban Aboriginal groups.*** *Australian Journal of Primary Health – Interchange* 2000: 6(1):6-14.

## 2. Frameworks and examples about conducting research in partnership with Aboriginal communities

- Couzos S, Lea T, Murray R, Culbong M. **'We are not just participants-we are in charge': The NACCHO ear trial and the process for Aboriginal community-controlled health research.** *Ethnicity and Health* 2005; 10(2):91-111.
- Henderson R, Simmons DS, Bourke L, Muir J. **Development of guidelines for non-Indigenous people undertaking research among the Indigenous population of north-east Victoria.** *Medical Journal of Australia* 2002; 176: 482-485.
- Holmes W, Stewart P, Garrow A, Anderson I, Thorpe L. **Researching Aboriginal health: experience from a study of urban young people's health and well-being.** *Social Science and Medicine* 2002; 54(8):1267-1279.
- Special Working Group of the Cree Regional Child and Family Services Committee. **Planning research for greater community involvement and long-term benefit.** *Canadian Medical Association Journal* 2000; 163(10):1273-1274.
- Elias B, O'Neil J, Sanderson D. **The politics of trust and participation: a case study in developing first nations and university capacity to build health information systems in a first nations context.** *Journal of Aboriginal Health* 2004; 1(1):68-78.
- Knight J, Comino E. 2007. **The Gudaga Story – describing the health of Aboriginal babies in Campbelltown.**
- Bailey J, Veitch C, Crossland L, Preston R (2006). **Developing research capacity building for Aboriginal & Torres Strait Islander Health Workers in health service settings.** *Rural and Remote Health Journal* 2006; 6: 556.
- Russell FM, Carapetis JR, Liddle H, Edwards T, Ruff TA & Devitt J (2005). **A pilot study of the quality of informed consent materials for Aboriginal participants in clinical trials.** *Journal of Medical Ethics* 31: 490-494.

### 3. Model agreements between communities and research teams including publication policies

Detailed agreements between researchers and participating Aboriginal community groups should always be negotiated before a project commences. These agreements should clearly spell out the research group's responsibilities to the community (including feeding back of results etc) and make clear provision for the rights of communities to control their participation in the study, withdraw at any time and have input into all publications arising from the study.

Some example research agreements are as follows:

- Desert Knowledge Cooperative Research Centre. **Aboriginal Research Engagement Protocol.** [http://www.desertknowledgecrc.com.au/resource/DKCRC-Aboriginal-Research-Engagement-Protocol\\_template-for-use.pdf](http://www.desertknowledgecrc.com.au/resource/DKCRC-Aboriginal-Research-Engagement-Protocol_template-for-use.pdf) (accessed online August 2012).
- Aboriginal Health and Medical Research Council. **Organisation consent form for research into Aboriginal health.** <http://www.ahmrc.org.au/index.php> (accessed online August 2012)
- The Aboriginal Health and Medical Research Council of NSW and The National Centre for HIV Social Research. 2006. **Sexually transmissible infections and blood borne viruses in Aboriginal communities in NSW: survey of knowledge, risk practice and access to services.**
- The University of Sydney. 2007. **Study of Environment, Aboriginal Resilience and Child Health (SEARCH) MOU.**

## 4. Ethics

### a) History and Role of the AH&MRC Ethics Committee

The AH&MRC Ethics Committee is registered a Human Research Ethics Committee under the National Health and Medical Research Council (NHMRC) legislation. The Committee is assessed annually by the NHMRC to ensure that it meets NHMRC Guidelines.

The role of the Committee is to assess research proposals affecting the health and wellbeing of Aboriginal people and to monitor the collection of data on Aboriginal health to ensure these activities will be conducted ethically.

The role of the Committee is endorsed within the NSW Aboriginal Health Information Guidelines (1998), which guides all NSW government agencies responsible for the management of Aboriginal health and health-related information. These Guidelines operate in conjunction with the NSW Aboriginal Health Partnership, a formal agreement between the NSW Government and the AH&MRC.

The Committee was first established in 1996 in response to the fact that for many years much research about Aboriginal people was invasive, inappropriate, unnecessary, and undertaken without Aboriginal community consultation or approval. The Constitution of the AH&MRC now requires it to operate an Ethics Committee.

During the past decade, over 600 research proposals and data publications have been referred to the Committee for approval.

#### *Composition of the Committee*

The composition of the AH&MRC Ethics Committee is in line with the recommendations of the requirements of the National Statement on Ethical Conduct in Research Involving Humans and of NSW Health for ethics lead agencies.

The Committee includes representatives of the AH&MRC Board, local Aboriginal Community Controlled Health Services (ACCHSs), and the Aboriginal community, together with members who have qualifications and long experience in health-related law, medicine, medical research, and clinical work.

In addition, the Committee has established an expert panel, consisting of experts in specific fields who can provide advice on individual research and data proposals and on broader issues affecting their field.

For more information about the AH&MRC Ethics Committee, see the AH&MRC website: <http://www.ahmrc.org.au/index.php> (accessed online August 2012).

### b) Assessment of Research and Data Collection Projects

The Committee assesses proposals in line with three documents, namely the ***AH&MRC Guidelines for Research into Aboriginal Health***, the ***National Statement on Ethical Conduct in Research Involving Humans*** and the ***NSW Aboriginal Health Information Guidelines***.



Researchers making an application to the Ethics Committee for approval should ensure that their application meets the requirements of these documents, especially in relation to Aboriginal community consent and the assessment criteria outlined below.

The AH&MRC Guidelines require that Aboriginal Community consent be obtained for research and data collection if one or more of the following factors apply:

- Aboriginality is a key determinant;
- data collection is explicitly directed at Aboriginal peoples;
- Aboriginal peoples, as a group, are to be examined in the results;
- the information has an impact on one or more Aboriginal communities; and
- Aboriginal health funds are a source of funding.

In evaluating applications for ethical approval of proposed research and data collection projects, the Committee ensures that the projects meet the requirements of the above three documents. In particular, the Committee assesses projects to ensure that:

- they will advance scientific knowledge and result in *demonstrated additional benefit* to Aboriginal communities;
- there is Aboriginal *community control* over all aspects of the proposed research, including research design, ownership of data, data interpretation, and publication of research findings;
- the research is to be conducted in a manner *sensitive to the cultural principles* of Aboriginal society;
- Aboriginal communities and organisations are to be *reimbursed for all costs* arising from their participation in the research process; and
- Aboriginal communities and organisations are able to benefit from the *transfer of skills and knowledge* arising from the project.

Researchers should work with ACCHSs and other relevant Aboriginal community groups from the earliest stages in the development of their application. This will help to ensure that the application meets the above requirements.

### **c) Committee Meetings**

The Committee meets every six weeks. An application must be received two weeks before a meeting to ensure that it will be considered by that meeting. For more information about the AH&MRC Ethics Committee, refer to the Ethics and Research page of the AH&MRC website:

<http://www.ahmrc.org.au/index.php> (accessed online August 2012).

## **5. Model consent forms and information materials**

The AH&MRC Ethics Committee provides the following model consent forms on their website:

- ***Individual Aboriginal consent form for researchers***
- ***Individual consent form for research into Aboriginal health***
- ***Organisation consent form for research into Aboriginal health***

These forms provide a detailed outline of the information that must be provided to communities and individuals on all participant information statements, as well as of the content required for consent forms.

## 6. Knowledge Dissemination

It is essential that the results of Aboriginal health research be feedback to participating Aboriginal communities.

- Brown J, Hunter E, Whiteside M. **Talking back: The changing nature of Indigenous health research feedback.** Health Promotion Journal of Australia 2002; 13(2): 34-39. (Document not available in public domain).
- Cooperative Research Centre for Aboriginal Health. **Planning for dissemination toolkit.**
- Cooperative Research Centre for Aboriginal and Tropical Health. **Thinking beyond the Project 2: Budgeting for research transfer and dissemination.**
- Ried K, Fuller J (2005). **Building a culture of research dissemination in primary health care: the South Australian experience of supporting the novice researcher.** *Australian Health Review* 2005; 29 (1): 6-11.
- Bowen S & Martens P (2005). **Demystifying knowledge translation: learning form the community.** *Journal of Health Services Research & Policy* 10 (4): 203-211.

Below are examples of the materials fed back to communities which participated in the Western Australian Aboriginal Child Health Survey:

- Telethon Institute for Child Health Research. **Western Australia Aboriginal Child Health Survey – The Story.**
- Telethon Institute for Child Health Research. **The health of Aboriginal children and young people - Wunan (Kununurra) ATSIC Region.**